A meeting of the NYeC Policy Committee was held on Oct. 22, 2019. Present either in person or via telephone were:

Art Levin, Center for Medical Consumers, Chair of Policy Committee  
Nance Shatzkin, Bronx RHIO  
Steve Allen, HealtheLink  
Amy Warner, Rochester RHIO  
Dr. Virginia Scott-Adams, NYS OPWDD  
David Nardolillo, NYS OPWDD  
James Kirkwood, NYS DOH  
Jonathan Karmel, NYS DOH  
Deirdre Depew, NYS DOH  
Dan Schiller, NYS DOH  
Lynn Dicerbo, NYS OMH  
Laurie Pferr, NYS Office for the Aging  
Dan Tietz, AIDS Institute  
Dr. John-Paul Mead, Cayuga Medical Associates  
Dr. Tom Mahoney, Common Ground Health  
Dr. David Cohen, Maimonides Medical Center  
Laura Alfredo, GNYHA  
Tom Hallisey, HANYS  
Linda Adamson, NYSTEC  
Val Grey, NYeC  
Cindy Sutliff, NYeC  
Nate Donnelly, NYeC  
Alison Birzon, NYeC  
Tijuana Summers, NYeC  
Bob Belfort, Manatt  
Alex Dworkowitz, Manatt

The meeting was called to order by Mr. Levin at 1 p.m.

I. Welcome and Introductions

Mr. Levin welcomed the Committee members, provided an overview of the meeting materials, and described the meeting agenda.

II. DOH Update

Mr. Levin introduced Mr. Kirkwood to provide an update. Mr. Kirkwood noted the DSRIP 2.0 waiver was out for public comment and invited Committee members to submit comments.
III. Executive Director Update

Ms. Grey provided an overview of New York State policy developments. She said that the executive branch is developing its budget and needs to close a Medicaid gap, so a series of videos have been produced highlighting the work of the Qualified Entities (QEs). She echoed Mr. Kirkwood’s statement that DSRIP 2.0 is out for public comment, and she said she was excited to see references to the SHIN-NY in the document.

Ms. Grey said that on the federal side, discussions about the Trusted Exchange Framework and Common Agreement (TEFCA), the plan for a national health information exchange (HIE), are still underway. She explained that the Office of the National Coordinator (ONC) had selected the Sequoia Project to serve as the Recognized Coordinating Entity (RCE) of TEFCA. Ms. Grey noted that the RCE would review the initial round of Qualified Health Information Network (QHIN) applications, but that other entities could qualify to become a QHIN if they were not accepted in the first cohort. She said that TEFCA envisions meaningful choice as consent, which is effectively an opt out right with meaningful education.

Ms. Grey said that the information blocking rule may go to the Office of Management and Budget by the end of the year, and therefore be released in 2020.

IV. Consent Workgroup Recommendations on Consent Recognition and New Form of Consent

Mr. Levin acknowledged the letter received from the Business Operations Committee (BOC) expressing concerns about the proposed SHIN-NY wide consent form. Mr. Levin provided a background on the work of the consent workgroup. He noted that the Policy Committee has been examining consent policies for a long time, which has included past proposals for a SHIN-NY wide consent and the approval of recommendations in 2017 to examine opt out. He said the Committee needs to consider interim steps toward achieving its goals.

Mr. Dworkowitz described the proposed policy on consent recognition. He explained that the policy language was largely the same as was presented to the Committee at a prior meeting, with the key difference being modified language regarding notice to patients.

Mr. Allen questioned the need for patient notification given that the provider already has access to data through other QEs though statewide patient record lookup (sPRL). Ms. Shatzkin agreed. Ms. Alfredo said there is a downside to providers of having to provide such notice, but questioned whether there was an upside. Dr. Cohen and Dr. Mahoney agreed.

Ms. Sutliff said that based on the consensus of the Policy Committee, the patient notification provision of the proposed policy would be removed, and the remainder of the policy would be sent to the NYeC board and DOH for approval.

Ms. Sutliff introduced the subject of the revised consent form. She said the form would give patients a meaningful choice, allowing them to consent to disclosures to nearly all SHIN-NY
participants but would also allow patients to cherry pick which providers should receive their information if they preferred to do so. She explained that the form would move the SHIN-NY in the direction of centralized consent management approach, which was approved by the NYeC board in 2017 as a mid-long term strategy on SHIN-NY consent.

Ms. Sutliff said that to address the BOC concerns, there would be a two-year on ramp for implementation of the proposed form of consent. In that time, assessments could be taken regarding the implementation approach. Ms. Warner asked how patient opinion would be addressed. Ms. Sutliff responded that patient viewpoints would be taken into account during the assessment process, and there would be a public comment period.

Mr. Dworkowitz described revisions to the form. He noted the draft form now includes the name of the QE, which could be contacted by the patient.

Ms. Warner said there would be many forms, including this form and a transferability form. Ms. Sutliff said there is no transferability form. Ms. Grey explained there would be no transferability form because the proposed policy changes are simply clarifying an interpretation that DOH has always had.

Dr. Mead questioned the need for the two-year delay, saying if the form is an improvement it should be implemented now. Ms. Sutliff responded that the two-year period is in response to concerns from the BOC, allowing for implementation that would not be rushed.

Ms. Shatzkin asked if they were still pursuing opt out. Ms. Grey responded that they are operating on parallel paths, exploring opt-out while also pursuing a SHIN-NY wide consent.

Mr. Allen said he liked the recent changes to the proposed form, in that the SHIN-NY is co-branded with a local QE.

Ms. Sutliff said she was looking for support from the Committee for a SHIN-NY wide form, and that the goal was to either switch to an opt-out system or implement a SHIN-NY wide form. She said approval for the SHIN-NY wide form approach would be sought from the NYeC board at their November meeting.

Mr. Levin suggested surveying QEs on their policies in regards to opt out and centralized consent management. Ms. Grey recommended raising these questions at the next BOC meeting.

V. Options for Community Based Organizations (CBOs)

Mr. Levin introduced the subject of CBOs’ role in the SHIN-NY. Mr. Dworkowitz explained that the focus of the discussion was on CBOs that are not covered entities under HIPAA. He described four different issues that could be addressed by the Committee: whether these CBOs always qualify as participants, CBO compliance with the HIPAA privacy rule, CBO compliance with the HIPAA security rule, and the types of protected health information that can be shared with CBOs.
Mr. Belfort explained there is some ambiguity as to how the HIPAA privacy rules apply to CBOs, since the disclosure exceptions are geared toward health plans and providers.

Ms. Warner said Rochester RHIO uses direct secure messaging with CBOs, and does not allow for queries. Ms. Shatzkin said the Bronx RHIO provides HIPAA training to some CBOs. She explained that if a clinician has consent and is accessing data through a query, the Bronx RHIO will let the user decide what the minimum necessary amount is, but if there is another delivery mechanism they try to ensure that the data transmitted is the minimum necessary. For example, data sent to transportation providers can be limited.

Ms. Pferr noted that the Office of the Aging subcontracts with CBOs, and that case managers – many of whom are not covered by HIPAA – often need to know a large amount of information. In contrast, transportation escorts need much more limited information. She noted that the Older Americans Act requires informed consent.

Dr. Cohen said they need to ensure that information was exchanged with CBOs in a manner that keeps the data secure.

Mr. Belfort said that given that the HIPAA disclosure rules are confusing in the context of CBOs, one alternative formulation is to require the CBO to use and disclose information consistent with the purpose for which the information was received.

Ms. Alfredo asked if the query function should be unavailable to CBOs. She said that GNYHA would be more comfortable if data was only pushed to CBOs.

Mr. Nardolillo said that under HIPAA, CBOs are not subject to a re-disclosure bar, but they are subject to such a bar under 42 C.F.R. Part 2 and other laws. He added that he was unsure if CBOs are aware of the limitations on re-disclosures.

Ms. Sutliff said that based on the discussion, Manatt would draft broad principles that would apply to the operation of CBOs in the SHIN-NY for discussion at the next Policy Committee meeting.

VI. Health Homes and 42 CFR Part 2

Dr. Cohen said that he views health homes as being considered treating providers for the purposes of 42 C.F.R. Part 2. He explained that case managers not only make phone calls, but they go out in the field and work with patients to define goals and a care plan.

Mr. Belfort explained that SAMHSA created a new concept of a “treating provider relationship” in the Part 2 rules, but didn’t connect the concept to any definition under HIPAA.

Mr. Allen noted that if all health homes obtained a 5055 consent form, then they would be able to receive Part 2 information even if they were not considered to have a treating provider relationship. Other Committee members agreed and noted that it is standard practice for health homes to obtain a 5055 consent form.
VII. Closing

Ms. Sutliff noted the next meeting is scheduled for November 15, and that the CBO issue would continue to be discussed.

Mr. Levin thanked the Committee members for their time and adjourned the meeting.